Research round-up

Gay men’s stories

This small-scale study examines research undertaken in 2005 to explore the rights of gay men to have sexual relationships. In the original research, 11 gay men with learning disabilities aged between 22 and 59 were asked to tell their stories.

The main themes were the discovery of love, a yearning to belong and the negative effects of social attitudes towards homosexuality among people with learning disabilities.

The authors state that the men’s sex lives depended on staff members’ attitudes towards homosexuality, which reveals how slow UK society is to acknowledge the sexual needs of people with learning disabilities.


Prader-Willi syndrome

Prader-Willi syndrome (PWS) is a complex, multidimensional disorder, whose effects on family life can be devastating. The early lives of people with the condition are dominated by hypotonia, which causes poor feeding and management difficulties.

As children with PWS grow older and their muscle tone develops, they often over eat, creating severe behavioural and obesity-related health problems. Other complex medical needs are also present in many cases.

This research compares family care of children with PWS with that of children with other complex needs. The authors found that the changing needs of individuals with PWS, and the long-term, unyielding supervision they require, affects the psychological health and quality of life of family members.

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The mothers of people with PWS experience greater stress, have a poorer quality of life, are more worried and must deal with more family conflicts than other mothers who care for family members with complex conditions.

Siblings are also affected, with 92% reporting severe post-traumatic stress symptoms, feelings of anger and sadness, increased hyper-vigilance, sleep problems and pessimism about the future.

According to the authors, these findings have implications for service provision. Respite services should be made available to relatives of people with PWS, and practitioners’ approaches should be sympathetic to the psychological needs of the parents and siblings of clients with the condition.


Learning disability census

The aim of this census was to describe inpatient care for people with learning disabilities to encourage a response to the Winterbourne View inquiry.

The census, which involved 3,250 service users, concludes that length of inpatient stay varies with inpatient age and that provision varies across regions. Most of the people included in the census are catered for in specialist learning disability settings, although about 20% are inpatients in mental health wards.

Contact between inpatients and their families or advocates is thought to be essential to positive patient experiences, yet only about 20% of inpatients are located within 10km of their homes. An action plan based on the census is due to be published.


On the web

Books Beyond Words present accounts of the most important life events of people with learning disabilities in accessible formats.

Used by practitioners and carers to encourage more thorough understanding of service users’ experiences, the books cover abuse, death and bereavement, dementia, falling in love, going to the doctor or hospital, the criminal justice system, and healthcare problems such as cancer, diabetes and epilepsy.

To date, 27 books have been published and most of them are free.

Website: tinyurl.com/od77hae